

A Regional Survey of Awareness of Inflammatory Bowel Disease among the Saudi Population

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Keywords

Inflammatory bowel disease · Ulcerative colitis · Crohn's disease

Abstract

Introduction: Inflammatory bowel disease (IBD) is common worldwide, including the gulf region. Early diagnosis of IBD can improve patients' outcomes. However, early diagnosis is dependent on patients' awareness of the disease to seek medical advice. This study aimed to survey the awareness of IBD in the general population of the western region of Saudi Arabia. **Methods:** A questionnaire about Crohn's disease (CD) and ulcerative colitis (UC) was distributed to the general public. A score of 1 was given for the right response and 0 for an incorrect response, giving a maximum of 3 and a minimum of 0 for the three questions in the questionnaire. **Results:** 1,304 participants responded. Twenty nine percentage had not heard or read about CD, while 19% had not heard or read about UC. The mean awareness level score was 1.72 ± 1.19 . Females showed a significantly higher score compared to males ($p < 0.001$). The age-group 31 to 40 had

the highest score ($p = 0.002$). Moreover, responders who had a PhD. showed significantly higher scores than those with other educational degrees ($p < 0.001$). Responders who dealt with CD or UC patients showed significantly higher scores than their peers ($p < 0.001$) for both. **Conclusion:** The general population in Saudi Arabia has an unacceptable level of awareness of IBD. Females, young adults (age-group: 31–40 years), educated individuals (with a PhD), and those who had dealt with IBD patients previously had better awareness compared to the rest of the population. National acts are essential to improve public awareness toward the disease.

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Introduction

Inflammatory bowel disease (IBD) is classified into Crohn's disease (CD) and ulcerative colitis (UC) [1]. It is defined as a chronic inflammation that affects the gastrointestinal tract. It can also have some systemic manifestations due to the inflammatory process [2]. IBD has shown increased morbidity and reduced quality of life among

patients [3, 4]. Some reports demonstrated that the quality of life is more reduced in the case of CD due to the need for more interventions as well as a higher risk of complications [3].

A recent systemic review of population-based studies demonstrated that IBD is now a global public health issue with surging incidence that will challenge and burden healthcare systems across the world [5]. The true incidence and prevalence of IBD are unknown in the Kingdom of Saudi Arabia (KSA) due to the lack of population-based studies. However, from regional retrospective studies, it is estimated that the incidence of both CD and UC is rising, reflecting the global trend [6].

Early diagnosis and management of IBD can reduce the severity of symptoms and the incidence of complications [7]. Nonetheless, delayed diagnosis is well recognized in IBD and is associated with significant complications [8, 9]. Diagnostic delay, which prolongs the disease duration, in addition, affects the response to therapy. Patients with shorter disease duration have better response to biologic therapy; the shorter the duration, the more significant the response, and those with <1 year of disease have the highest response to therapy [7, 10]. Furthermore, early initiation of biologics in IBD has shown to improve clinical outcome by reducing the need for hospitalization and colectomy with the potential to alter the disease course [11].

When different aspects of the delay in diagnosis were analyzed, it was noted that patient-related factors were considerably prolonging the delay [12]. One of the explanations could possibly be the lack of awareness among patients of the likely IBD symptoms, leading to a delay in seeking medical advice. A public opinion poll survey conducted in Austria highlighted the lack of nationwide IBD awareness with up to 80% of responders being ignorant about IBD [13].

A study in the KSA did find a long delay in diagnosis of IBD in a pediatric population, and delay in patients seeking healthcare was a major factor. One of the suggestions of the authors to shorten the delay was to raise awareness of the disease among the general public [7]. Due to the rising incidence of IBD and significant costs associated with its healthcare, annual IBD patient education and awareness campaigns are held in major cities across KSA. However, there is a lack of data in the medical literature about the awareness of the general population toward CD and UC in the KSA. Therefore, the objective of this study was to understand the general Saudi population's awareness of IBD.

Materials and Methods

Study Design

This was a cross-sectional observational study that was carried out in the western region of Saudi Arabia. There are no validated questionnaires addressing the awareness of IBD in the general public; therefore, a questionnaire that was previously used in an Austrian study for similar purpose was used [13]. This questionnaire was translated into Arabic according to WHO criteria. The questions were then reviewed by experts in IBD for accuracy and appropriateness. Following this step, the questions were piloted on lay public persons to test for appropriate comprehension. This exercise led to some modifications of the original questionnaire with simplification of the questions and addition of an extra question on therapy. Participants aged above 16 years were eligible to participate. On the other hand, participants with a history of IBDs were excluded. Only participants who filled the survey were included in the analysis.

Data Collection

The above questionnaire itself was disseminated to members of the public in the western region of Saudi Arabia through holding awareness stands and stalls at major family-gathering places like shopping malls, hospitals, and parks and community centers like mosques. The responses to the questionnaire were transferred directly to electronic devices to minimize loss of response. In addition, internet-based monkey survey, a software that helps to create customized surveys, was used to build the questionnaire online. This online questionnaire was disseminated via the internet and social platforms through a link by an invitation to participate in the survey.

The questionnaire collected demographic data, educational level, age-group, gender, and employment status of the participants. Additionally, general questions about CD and UC were included (see online suppl; for all online suppl. material, see www.karger.com/doi/10.1159/000529318 for English and online suppl. 2 for Arabic)

Statistical Analyses

Data were expressed as frequencies and percentages for categorical variables and as means and standard deviations for continuous variables which were normally distributed. Every correct response to each question was assigned one point, while wrong answers were assigned zero point, which were then added to calculate the total score. The questionnaire consisted of three questions, and the participants were requested to give a single response to each of them as either negative or positive. Hence, the total score ranged from a minimum of 0 to a maximum of 3. One-way ANOVA analysis was applied to compare means among different groups. All *p* values <0.05 were considered statistically significant. IBM SPSS (Statistical Package for the Social Science; IBM Corp, Armonk, NY, USA) was used to carry out all statistical analyses, version 26 for Microsoft Windows.

Ethical Considerations

All participants were provided with detailed information about the study, and only those who voluntarily consented were recruited. Confidentiality was maintained, and the patients were identified by research serial number only. Ethical approval was obtained from King Abdullah Medical City, Makkah Institutional Review Board, that has been accredited by the Association for the Accreditation of Human Research Protection Program.

Table 1. Sociodemographic data of responders to the questionnaire

Parameters	Count	%	General Saudi Population [§] (%)
Gender			
Male	467	35.8	19,363,656 (57)
Female	837	64.2	14,747,165 (43)
Age-group			
<20 years	206	15.8	2,405,249 (7)
20–29 years	494	37.9	5,634,259 (16.5)
30–39 years	218	16.7	6,786,264 (19.9)
40–49 years	204	15.6	5,854,170 (17.2)
50–59 years	132	10	3,055,306 (9)
>60 years	50	3.8	1,999,371 (5.9)
Employment status			
Employed	537	41.2	
Unemployed	200	15.3	
Retired	68	5.2	
Student	361	27.7	
Educational level			
Illiterate	10	0.8	
Primary	15	1.2	
Intermediate	47	3.6	
Secondary	415	31.8	
Bachelor	709	54.4	
Masters	69	5.3	
PhD	39	3.0	

138 (10.6%) responses were filled in physically at various awareness campaigns. [§] www.stats.gov.sa.

Results

Only participants who finished all the questions in the questionnaire were included. One thousand eight hundred and nine participants from the western region in Saudi Arabia answered the questionnaire; of these, five hundred and five were incomplete and excluded. One thousand three hundred and four participants were hence included in the final analysis. 138 of these questionnaires were filled in physically at various awareness campaigns organized as mentioned above (Table 1). The demographics of participants and analysis of the questionnaire are shown below.

General Characteristics of Responders

Out of the 1,304 participants, age was categorized into six age-groups, starting with age below 20 years and ending with age above 60 years. Most of the responders (35.4%) were from the age-group between 21 and 30 years old. The average age of responders among the whole cohort was 34.19 ± 14.02 years. Additionally, 64.2% of the whole cohort were females. Compared to the general Saudi population, our study cohort was more representative of females and a younger age-group (Table 1)

Turning to the educational level, only 0.8% of the responders were illiterate, while 54.4% had a bachelor's degree. Also, 41.2% were employed. All demographic data are shown in detail in Table 1.

Awareness about CD

Participants were asked a set of questions to identify their awareness of CD. Twenty nine percentage of the responders had not heard or read about the disease, while 32.4% had some information about CD. Moreover, 37.1% of the responders knew that CD affects the intestine, while a quarter of the responders (25%) knew that there is a medical treatment for CD as shown in Table 2.

Awareness about UC

Like CD, participants were asked three questions on UC to evaluate their awareness of the disease. Around 19% of the responders had not heard or read about the condition, while 27.5% had heard about it somewhere. Moreover, 73.8% of the responders knew that UC affects the intestine, and 52.5% of the responders did not know if there is a treatment for UC, as shown in Table 3.

Table 2. Responses toward awareness about CD

Responses	Score assigned	Count	%
Did you hear, read, or deal with Crohn's disease?			
I did not hear or read about it	0	378	29.0
I heard about it somewhere	1	268	20.6
I got some information about it	1	423	32.4
I dealt with somebody with the disease	1	95	7.3
I do not know	0	140	10.7
Crohn's disease can affect			
Head	0	14	1.1
Heart	0	5	0.4
Liver	0	18	1.4
Intestine	1	484	37.1
It is an infectious disease	0	285	21.9
I do not know	0	498	38.2
Is there medical therapy for Crohn's disease?			
Yes	1	326	25.0
No	0	222	17.0
I do not know	0	756	58.0
Total score	3		

Table 3. Responses toward awareness about UC

Responses	Score assigned	Count	%
Did you hear, read, or deal with Ulcerative colitis?			
I did not hear or read about it	0	248	19.0
I heard about it somewhere	1	358	27.5
I got some information about it	1	318	24.4
I dealt with somebody with the disease	1	165	12.7
I do not know	0	215	16.5
Ulcerative colitis disease can affect			
Head	0	2	0.2
Liver	0	21	1.6
Intestine	1	963	73.8
It is an infectious disease	0	16	1.2
I do not know	0	302	23.2
Is there medical therapy for ulcerative colitis?			
Yes	1	479	36.7
No	0	141	10.8
I do not know	0	684	52.5
Total score	3		

Awareness of IBDs

The total score for correct answers was calculated and compared over different variables; the average score was 1.72 ± 1.19 , with a minimum score of 0 and a maximum score of 3. The comparison revealed a significant difference between males and females, where females showed a significantly higher average score than males (p value <0.001). Also, different age-groups had a significantly different awareness of IBD (p value = 0.002), with the age-

group between 31 and 40 showing the highest average score. Moreover, the awareness level differed significantly over different educational levels. Participants with a PhD showed significantly higher mean scores compared to the other educational degrees (p value <0.001)

Furthermore, participants who dealt with CD patients or UC patients showed significantly higher scores compared to their peers, with p values <0.001 for both, as shown in Table 4. In addition, the mean of the total score

Table 4. Awareness level compared with different variables

	Mean	SD	<i>p</i> value
Gender			
Male	1.47	1.14	<0.001*
Female	1.87	1.20	
Age categories			
<20 years	1.48	1.05	0.002*
21–30 years	1.79	1.22	
31–40 years	1.89	1.24	
41–50 years	1.79	1.24	
51–60 years	1.66	1.20	
>60 years	1.38	0.92	
Employment status			
Employed	1.84	1.27	0.06
Unemployed	1.67	1.18	
Retired	1.62	1.12	
Student	1.67	1.10	
Educational level			
Illiterate	1.50	1.27	
Primary	1.00	1.13	
Intermediate	1.72	1.19	
Secondary	1.53	1.12	
Bachelor	1.79	1.18	
Masters	1.84	1.37	
PhD	2.77	1.31	
Did you hear, read, or deal with Crohn’s disease?			
I did not hear or read about it	1.29	1.09	<0.001*
I heard about it somewhere	1.67	1.08	
I got some information about it	2.08	1.15	
I dealt with somebody with the disease	2.57	1.19	
I do not know	1.36	1.19	
Did you hear, read, or deal with ulcerative colitis?			
I did not hear or read about it	1.07	1.02	<0.001*
I heard about it somewhere	1.78	1.09	
I got some information about it	2.37	1.00	
I dealt with somebody with the disease	2.43	0.97	
I do not know	0.89	1.06	

* Statistically significant.

of the three questions pertaining to UC was significantly higher when compared to questions regarding CD, 1.75 (SD 1.04) versus 1.22 (SD 1.00), respectively (*p* value <0.001) (online suppl. Fig. 1)

Discussion

Since the incidence of IBD is raising worldwide with cure in sight, it is imperative to recognize and diagnose the disease at an early stage to ensure effective control of the disease and avoid complication. In this context, it is important to know about the awareness of the lay public about IBD and identify any ignorance that may help to implement

an appropriate education plan. This in order may enlighten the lay person to seek prompt healthcare assistance for early diagnosis. Hence, the present study aimed to assess the awareness of the general population in Saudi Arabia toward IBDs (CD and UC). The study demonstrated that the average score of our population was 1.72 ± 1.19 , with a minimum score of 0 and a maximum score of 3.

There was a significant difference between males and females, where females showed a significantly higher average score compared to males (*p* value <0.001), and different age-groups had a significantly different awareness of IBD (*p* value = 0.002), with the age-group between 31 and 40 years showing the highest average score. Moreover, the awareness level differed significantly over different educa-

tional levels. Participants with a PhD showed significantly higher mean scores compared to those with other educational degrees (p value <0.001). Furthermore, participants who dealt with CD or UC patients showed significantly higher scores than their peers, with p values <0.001 for both.

Disease-specific knowledge of IBD patients has been widely studied in different countries using a validated questionnaire of Crohn's and Colitis Knowledge Score [14]. The knowledge of IBD, in addition, has been evaluated in specific settings like primary health care. Alharbi et al. noted that the knowledge level of 200 primary care physicians in the western region of KSA was low, and through education of IBD, the awareness improved significantly. IBD-specific education did translate into better management, by making physicians more comfortable about using specific IBD therapies like steroids and immunomodulators. Moreover, physicians with higher qualification were much more comfortable in prescribing medicines for IBD [15]. However, another study by Tan et al. [16] carried out in Australia showed that the knowledge score among 409 PHC physicians was higher even without being educated on IBD-specific knowledge. These differences could be due to various reasons. PHC physicians in Australia usually look after stable chronic disease patients like IBD. This is not the case in KSA. The lower prevalence of IBD, minimal availability of information in Arabic language, and patient supportive organizations may be the other reasons.

However, there is scarcity of the literature evaluating the awareness of IBD in the general public. We identified only a couple of studies that did evaluate awareness of the public about IBD. Groshek et al. carried out a national online survey of 1,200 participants in the USA on the awareness of IBD and demonstrated that the lay public scored a mean of 5.5 (SD 2.7) on a "familiarity" scale of 10 and was considered to be a low score. In addition, low awareness was associated with high stigmatization of IBD that was worse than other diseases like alcoholism and HIV. Furthermore, the level of knowledge was tested on 12 questions of causes, symptoms, and cures of IBD, and only 55% (mean: 6.58/12) responded correctly, with 86% responding inappropriately to nearly 8 of the 12 questions. However, those with higher education had a statistically better score [17]. Our study showed a similar level of knowledge among the public ($1.73/3 = 57\%$) that was significantly better in people with higher qualification.

Another study, a nationwide survey by Angelberger et al. evaluated the public awareness toward IBD in 1,001 individuals from the Austria and concluded that the knowledge of the population was poor [13]. 69% and 80%

had not heard or did not know about CD and UC, respectively. Similarly, 64% and 73% did not know the organ affected by CD and UC, respectively. In contrast, only 40% and 36% of our study population had not heard or did not know about CD or UC, respectively, and only about a third did not know the organ affected in CD or UC. These differences may be a reflection of a high proportion of females and younger participants in our study who were more knowledgeable. In addition, the survey in Austria was exclusively in person, whereas our study used a combination of personal and online survey.

One of the limitations of our study is that the questionnaire was administered to volunteers. This introduces non-probability and self-selection biases, leading to misrepresentation of the general population [18]. In addition, we did not have the means to record the total number of participants who accessed our questionnaire (denominator), precluding estimation of the response rate, again limiting generalizability. Though it is difficult to quantify these biases, the recruitment of a diverse group of participants in our study from different demographics, educational status, and localities tries to mitigate this. Furthermore, our questionnaire used to test public awareness was not externally validated and thus limits its generalizability. It nevertheless does capture the basic knowledge that might be accepted of a lay person and has been previously used. In addition, the questionnaire lacked a clear cutoff score to identify appropriate level of awareness. This is a challenge that questionnaire-based studies like these face [14]. Nevertheless, this study may inspire further such research with refinement, leading to more accurate questionnaires.

Females in our population were more aware of IBD. Though the literacy level of the females was not different from their counterparts, they however were more likely to be in the age-group of 31–40 years than the males. This age-group had better awareness than others, and on further analysis of their response to the questionnaire, it was noted that most of them answered positively to the question "I got some information regarding this disease and I read about it." Given that the majority of the population of KSA uses social media with the similar age-group being the largest consumer, it may be presumed that the social media usage may have resulted in better awareness of IBD. This study has given us an insight into the level of awareness and the characteristics of the population group more informed about IBD in our region. Based on this, we have targeted our awareness programs more toward different age-groups and those with lesser qualification along with producing more handouts apart from focusing on social media.

Findings on lack of awareness of IBD as suggested by our study maybe pertinent to other parts of the world that are not only culturally and linguistically similar like the Arab world but also have a comparable human development index as these factors influence the level of awareness. Appreciating the poor awareness of IBD may help these nations to implement programs to improve the knowledge base of IBD that may ultimately better prepare the healthcare systems to manage the rising incidence.

Conclusion

This is the first study to evaluate the awareness of the Saudi population toward IBD and showed a low level of awareness among different community sectors. Females, young adults, and highly educated individuals who dealt with patients previously had better awareness compared to the rest of the population.

These findings reveal the basic awareness of IBD among the public in KSA and should be considered by decision-makers and societies to organize campaigns for the general public to improve their awareness of the disease, which will have positive implications on the early diagnosis and treatment of the disease and reduce health care costs.

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Statement of Ethics

The study was reviewed and approved by King Abdullah Medical City, Makkah Institutional Review Board, that has been accredited by the Association for the Accreditation of Human Re-

search Protection Program (IRB approval number 19-596). As this was an electronic questionnaire-based study, the participants were given full information about the study including a statement of consent. The participants were requested to read this information and the statement of consent before answering the questionnaire. Participants who read this statement of consent by ticking it and proceeding to answer the questionnaire were deemed to have provided informed consent.

Conflict of Interest Statement

The authors have no conflict of interest to declare.

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Author Contributions

Yaser Meeralam and MK Shariff participated in concept, design, literature search, data acquisition, data analysis, manuscript preparation, manuscript edition, and review. Adnan Al Znanabgi, Mosily Mahmoud, Yusuf Qari, Mona Al Saedi, and Abdulaziz Tashkhandi participated in literature search, data acquisition, manuscript preparation, manuscript edition, and review. Mohmoud Eliouny, Abdulwahab Neyazi, and Ghadeer Al Hazmi participated in data acquisition, manuscript edition, and review.

Data Availability Statement

All data generated or analyzed during this study are included in this article and its supplementary materials. Further inquiries can be directed to the corresponding author. A preprint version of this article is available on medRxiv: Yaser Meeralam, Adnan Al Znanabgi, Mosily Mahmoud, Yusuf Qari, et al. A Regional Survey of Awareness of Inflammatory Bowel Disease among the Saudi Population. doi.org/10.21203/rs.3.rs-123583/v1 (preprint) Nov 2020.

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